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Parental response to Universal Newborn Hearing Screening

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PARENTAL RESPONSE TO UNIVERSAL NEWBORN HEARING SCREENING

by

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Abstract

Universal Newborn Hearing Screening (UNHS) has become the standard of care in the United States. In January 2002, Missouri State law mandated UNHS for every child prior to discharge from the birthing facility. Much research is available with respect to techniques, protocols, and instrumentation to optimize pass and refer rates. However, relatively little research has been carried out on parental response to UNHS.

The objective of this study was to describe parental response to UNHS. Differences in parental reaction for pass and refer results within well-baby, special care, and neonatal intensive care nurseries were examined via telephone survey. The telephone survey was administered to 60 parents whose infants passed the hearing screening and 60 parents whose infants referred on the hearing screening. Parents were surveyed between one and three weeks after the initial screening was completed. More negative emotional responses were obtained across nurseries from parents whose infants referred on the screening. During the period from one to three weeks post screening the emotional responses from parents whose infants referred progressed from 52% negative responses to 19% negative responses. Results indicate that verbal explanation of the screening results were the most readily understandable to parents. Although the screeners and nurses was the most likely informants of screening results, parental preference is that a physician to relay this information. In general, a majority of parents believed that screening prior to discharge was best. However 48% of parents whose infants referred preferred that the screening be done at a later time (e.g. first "well-baby visit").

Introduction

Forty-two states plus the District of Columbia have implemented Newborn Hearing Screening (UNHS) programs through either early hearing detection and intervention laws or

voluntary compliance programs (ASHA website).. These programs currently screen the hearing of over 85% of newborns born in this country (ASHA website). Evidence has shown that early identification and, in turn, intervention significantly improves the language and educational outcomes of children with hearing loss (Bess, 1993; Bess & Paradise, 1994; Harrison & Roush, 1996; Raimondo, 1999; Yoshinaga-Itano, 2000). The objective of UNHS is identification by three months of age with intervention in place by six months of age (NIH, 1993).

Support for UNHS has not been universal. One concern is that parental anxiety elicited by the screening experience may negatively influence parent-infant bonding. Another issue is the cost associated with the false-positive rate (Sorenson et al, 1984; Tluczek, 1991; Baroni et al, 1997; and Tharpe & Clayton, 1997). With respect to screening of newborns for metabolic disorders (or other medical such as cystic fibrosis and phenylketoneuria), studies have shown that the critical period for parent infant bonding is in danger of being affected as a result of the anxiety experienced by the parents due to the results of the screenings (Sorenson et al, 1984; Tluczek, 1991; Baroni et al, 1997; and Tharpe & Clayton, 1997).

Bodegard et al (1983) reported on the reactions of 102 families with infants who received a false-positive result on a congenital hypothyroidism screening and found that a false positive result triggered a "psychic crisis" in the majority of families. Sorenson et al (1984) reported on parental response to repeat screening with false-positive results for phenylketonuria. In contrast to Bodegard et al (1983), they found that parents who were aware that their infant was being re-screened because of a fail on the initial screening were no more anxious or depressed while waiting for the results than parents whose infants passed on the first screening. Thirty-six percent did report concern about their infant's health due to the need for re-screening. This concern did not appear to be related to the parents' knowledge of the initial results, but rather due to the

amount of information they had on the screening process and its significance for the health of their child.

With respect to UNHS, Bess and Paradise (1994) expressed concern stating, "Additional diagnostic and inappropriate therapeutic procedures, parental misunderstanding and anxiety, as well as unfavorable labeling..." can all stem from a false positive result. Stach and Santilli (1998) suggested that parental anxiety resultant from false positive results in UNHS programs is of significant concern. However, Sutten et al 1994 point out - "Some degree of parental anxiety is not unexpected during a screening, it only becomes a problem when it becomes severe and affects a large proportion of those screened."

It is plausible that if the experience with and results from other types of newborn screenings can generate enough anxiety in parents to influence the critical parent-infant bonding period, that UNHS could potentially cause similar effects. Before discussing specific studies aimed at parental anxiety due to false positives in UNHS, it is important to consider that the number of parents potentially affected is influenced by the false positive rate. The percentage of infants who refer in the well-baby nurseries is approximately 19 per 1000 (1.9%) (Stach & Santilli, 1998). The percentage of over- estimation of hearing loss by screening protocols in this environment is approximately 17 per 1000 (1.7%) (Stach & Santilli, 1998). Alternately, calculating posterior probability, the probability that an infant who refers in this population truly has hearing loss is only 11% (Turner, 1991).

In the neonatal intensive care unit (NICU) the refer rate ranges from five percent to 15% (Stach & Santilli, 1998). Based upon a five- percent false-positive rate the over-referral is approximately 30 per 1000. The posterior probability that the infant truly has hearing loss in this environment is 40%. If we calculate over-referral and posterior probability using the 15% false-

positive rate, the over-refer rate increases dramatically to 130 in 1000 and the incidence of true hearing impairment falls to 13% (Stach & Santilli, 1998).

deUcategui and Yoshinaga-Itano (1997) analyzed the emotional impact of UNHS on 69 parents whose infants referred on initial UNHS from two Colorado hospitals from January 1995 through April 1996. One hospital served a majority middle to upper socioeconomic population while the second hospital served a lower socioeconomic population, the majority of patients being Medicaid recipients. The authors used a Likert-type questionnaire, in which the parents responded to questions with, "a lot like me," somewhat like me," not much like me," and not at all like me." Four questions guided the study:

> 1) "To what extent do parents of children referred for further hearing testing report negative emotional responses?"
> 2) "To what extent do parents of children who referred for further hearing testing report positive emotional responses?"
> 3) "Is emotional response to UNHS dependant upon hospital type?"
> 4) "Is the emotional reaction to UNHS different for parents of children who have confirmed hearing loss as compared to parents of children who are determined to be false referrals?"

deUcategui and Yoshinaga-Itano (1997) reported that generally parents reported positive emotions in regard to UNHS. The most frequently reported positive emotion was "informed" (81%). Eighty-nine percent reported "no blame," 84% reported feeling "not guilty", and 78% reported feeling "no anger that the referral happened to them and their infant." Fourteen percent of parents expressed negative emotional reactions to the referral process. Families from both hospitals reported some negative emotions, but "on average" the degree of negative emotion experienced was rated as, "not at all" (hospital 1) and "not much" (hospital 2). Ten parents expressed "anger", of which five explained their anger as a result of not being comforted by the staff performing the screening. Once hearing loss was confirmed, parents responded with a

higher level of impatience and frustration with the screening process than during the time between the initial screening and diagnostic testing. These parents also experienced more anger, depression, and confusion than parents whose infants had a false-positive result. In regard to performance of the professional, eight percent reported negative feelings regarding the volunteer and six percent reported negative feelings regarding the audiologist. The authors suggest this finding means that parents feel comfortable with either of these professionals performing and relaying screening results. It is also interesting to note the 25% of the entire population of infants that referred on the screening did not return for follow-up diagnostic testing. The authors conclude that there is no evidence from this data that UNHS places any unnecessary harm on parents. In contrast, the majority of parents reported that due to UNHS they became more aware of their child's speech, language, and auditory development. deUcategui and Yoshinaga-Itano (1997) concluded that UNHS could be performed in a way that even with false-positives and confirmed hearing losses, negative emotions can be minimized.

Watkin et al (1998) investigated the effects of UNHS on maternal bonding with 288 mothers whose infants were cared for in a well-baby nursery. A forced-choice questionnaire was distributed after the initial screening and after re-screening at six weeks. Satisfaction with the program and degree of anxiety at various stages of the screening protocol was examined. Watkin et al (1998) also examined the proportion of parents who admitted to reading the written information they received at the time of the initial screening, the percentage of mothers who accompanied their infant to the screening, and the appropriateness of the age at which the child was screened. Data for passes and refers were pooled. At the initial screening, 28% of mothers had some degree of anxiety, 15% reported being "fairly worried," and 0.7% reporting "very worried." At this screening an additional 40% reported being "not worried" and 44% reported

being "hardly worried." At the time of the re-screening, of those who reported some degree of worry at the initial screening, two percent reported being "fairly worried" while 3.5% reported they were "very worried." At this time, 56% of those worried at the initial screening were "no longer worried" and 37% reported being "hardly worried." The result of the initial screen and the re-screen also did not influence the anxiety state of the mothers. No mothers commented on being worried due to a lack of information; however, over one-third of mothers reported not reading the information they were given. Eighty-four percent of mothers reported that screening in the maternity unit was appropriate.

Magnuson and Hergils (1999) examined parental views on newborn hearing screening in well babies by personal interview eight-to-twelve months after completion of the screening process. Three groups of parents were interviewed: parents of infants who passed after the first screening (21 parents of 10 infants), parents of infants who passed after a re-screen (20 parents of 10 infants), and parents of infants who received more than two screenings (8 parents of 4 infants). All parents were given a hearing-screening brochure at hospital admission along with a verbal explanation of the screening procedure and results during the screening. Twenty-nine (50%) parents did not remember receiving the hearing-screening brochure. The most common response for why they could not remember the brochure was; "there were so many other things around." Those parents who read the brochure at a later date typically reported it to be informational and interesting. Twenty parents (41%) reported the desire to have the information before hospital admission. Slightly more than half of parents reported that the right time to be given information was in direct connection with the screening. All parents considered the verbal information given at the time of the screening to be valuable. Response to hearing screening in general was positive in all parents. Every parent expressed the desire to understand and help their child if a hearing

impairment was found. In the case that the infant passed the first or second screening, parental reaction was positive and pleased. It was only in the cases (ten parents) that the child had to be screened more than two times that anxiety was aroused. At least one parent was present in all cases and for 92% of cases both parents were present. The authors report that parental presence "promotes an attitude of reassurance and interest." With respect to the timing of the screening, two parents reported wanting the initial screening at two weeks of age, rather than screening before discharge.

Clemens et al (2000) conducted a structured, telephone survey that was administered to 49 mothers of infants who failed an initial screening and had subsequently completed an out-patient follow-up screening in a well-baby nursery (WBN). Clemens et al (2000) examined the following: degree of anxiety experienced, whether or not parents perceived treating their infant differently between the two stages of the screening process, general attitude toward UNHS, the best professional to discuss results, the adequacy of the explanation received, and the degree of residual anxiety experienced. The majority of parents reported that the screening program was a "good idea." Although there was a high level of anxiety before stage two screening, 91% of families reported treating their infant normally during this time. Only nine percent reported treating their infant differently between the initial screening and the follow-up. Only 14% reported any degree of residual anxiety after their infant passed the follow-up screening. The study found that although initial anxiety is common, it dissipates quickly after the infant passes stage two screening.

Hergils and Hergils (2000) questioned 83 parents with a written questionnaire that was distributed in three clinics in Sweden at the five-to-six month well-baby health check. The questionnaire consisted of open-ended questions as follows:

How were your feelings regarding the hearing screening?
Did the screening raise any questions or thoughts?
Are you positive or negative to this screening? Please explain!
Did you find the information to be sufficient about the screening?
Did you find opportunity to ask any questions?
More comments?

In regard to feelings regarding the hearing screening 76 (92%) parents were satisfied with the screening, three (3%) were neutral and one (1%) did not remember. Regarding positive or negative feelings toward this screening, 79 (95%) were positive toward the screen, one was ambivalent and three had a negative attitude. With respect to the information provided, 64 (77%) said that information was sufficient, six (7%) were undecided and nine (11%) did not find the information to be sufficient. Most of the parents who reported anxiety were parents of infants who referred on the screening (6 of 10). Although these parents were anxious, seven of the ten were positive about the screening. They were, however, more critical about the information given. Reasons for being negative about the screening included the following: anxiety aroused by repeated screening, screening situation was too demanding (too long and infants had to be quiet for a substantial period of time), the outer ear canal had to be cleaned, probe insertion must be a "horrible" experience for the newborn, screening should not need to be so early, dissatisfaction with the information provided. The authors conclude that efforts should focus on the following: expend more time on the infants who refer on screening and require audiologic assessment, try to reduce time until re-screening and diagnostic procedures, and improve the pre-screening information.

Stuart et al (2000) administered the Parenting Stress Index (PSI) screening and assessment questionnaire by telephone, one month after nursery discharge. Participants were mothers of 20 full-term, well babies who passed their hearing screening and 20 full-term, well babies who failed

the screening. The PSI was designed to "assess the relative magnitude of stress in a parent-child dyad, at risk for dysfunctional parenting, and at risk for development of emotional pathology" (Stuart et al, 2000). The 20 infants who failed the initial screening were all re-screened within one month. Stuart et al (2000) reported that during the first month after hospital discharge mothers of infants who failed the initial screening were not significantly more predisposed to stress than mothers of infant who passed the initial screening. The study also indicated that indices of stress remain stable after the 1st year of diagnosis of hearing loss and there is little, if any, difference in the degree of stress experienced between mothers of infants with and without hearing loss in the first year after diagnosis. The authors conclude that anxiety induced interference from UNHS with emotional attachment is minimal.

Vohr et al (2001) examined maternal worry with UNHS in well babies in a cross-sectional study using a written questionnaire in both 1997 and 1999. The questionnaire was completed prior to discharge in one group (N=307). The other group was approached two-to-eight weeks after discharge when they returned for a re-screen (N=40). The "prior to discharge group" was not aware of the screening results and the "re-screen group" was not aware of the re-screen results at the time they completed the questionnaire. When asked "Were you worried?" zero percent (1997) and nine percent (1999) were not worried prior-to-discharge. With respect to "worry," the researchers used a Likert scale in response to the question, "How anxious or worried were you about the hearing screening?" Ratings were as follows: not worried, mildly worried, somewhat worried, worried, and very worried. Degree of worry increased with return for re-screen. For example, prior-to-discharge 3.8% (1997) to 4.0% (1999) were "worried" or "very worried." In contrast, at the time of re-screen 23% (1997) and 17% (1999) were "worried" or "very worried." The authors also report that despite multiple attempts to educate mothers about the hearing

screening prior to admission, only 29% (1997) and 27% (1999) learned of the screening prior to hospitalization. The efforts to inform parents included the following: hearing screening brochures in the pre-admission packet, hearing screening brochures in prenatal classes, video of a screen on the TV/video channel in the room and a hearing screen brochure placed at the crib at the time of the screen. Given these efforts, awareness of the screen during hospitalization rose to 67% (1997) and 73% (1999). With respect to the population in the current study, it was of interest that mothers with disadvantaged socioeconomic status had a higher risk of referring on the initial screen.

Weichbold et al (2001) conducted a study of 90 mothers to investigate if offering parents varying degrees of information on the hearing screening procedures and results affects maternal attitude toward UNHS. The mothers were questioned in-person with a "semi-standardized" questionnaire. Attitude toward screening was based upon the following variables: amount of information given, involvement in the screening process (aware screening occurred, aware of results, present at screening). The majority of mothers (84%) favored UNHS when fully informed and aware of the procedure. This study divided mothers reactions toward UNHS into two groups, "advocates" and "skeptics." The authors defines "advocates" as mothers who answered "Yes." to the question, "Should UNHS be performed despite the possibility that parents become worried by false-positive screening results?" Mothers who answered this question, "No." were labeled "Skeptics." The mothers were also divided into two groups--those who were present at the screening and those who were not present at the screening. Those who were present received the most extensive information while those absent received restricted information. Of the 46% of mothers who were present at the screening only five percent were "skeptics." Of the 54% of mothers who were absent during the screening, but knew the screening result 12% were

"skeptics." Weichbold et al (2001) noted that if infants needed to be rescreened mothers who were better informed experienced less anxiety than those with less information.

Weichbold et al (2001) reported on the of the level of maternal anxiety expressed immediately following a false-positive result on the initial screening and the level of maternal anxiety expressed following a fail on the re-screening one month later (N=43). For infants who initially referred, 59% of mothers were not at all concerned and 27% reported being "a little concerned." Fourteen percent of mothers were "considerably or even very worried." For infants who referred on both the initial screen and the re-screen, 42% of mothers reported no concern at all and 37% reported "a little concern." Twenty-one percent of mothers with knowledge that their infant referred on the rescreening, were "considerably worried" or "very worried". Thus, the majority of mothers are not alarmed by a false-positive result. It was only after referring on the initial screening and the re-screening that maternal worry increased. Change in anxiety levels could not be predicted based on whether or not mothers were counseled on the fact that even if their infant referred on the screening, there was not a high percentage chance that the infant would have the disorder.

In a retrospective study Luterman et al (1999) examined the attitudes toward UNHS in a population of parents of children with a previous diagnosis of deaf or hearing impaired. The written survey was distributed to over 300 families of which 75 responded. The children of the parents ranged in age from three months to 24 years. The large majority of these parents expressed a desire to have their child's impairment known to them at birth. The overwhelming percentage of the parents also indicated an audiologist is a qualified professional to discuss the results of hearing screening with the parents. In general, independent of their child's current age, the majority of these parents support early identification. Luterman et al (1999) suggest that the

best way to avert negative emotional experiences is to have immediate access to unbiased information, to meet other parents of hearing impaired children, and to have time to process the experience and the amount of information received upon diagnosis.

In summary, reported studies noted some degree of "maternal worry" at the time of the re-screen in reference to the initial screen. Magnuson and Hergils (1999) suggest that failure of the first re-screen is the "critical point" for maternal anxiety. The studies reviewed also reported that lack of information and education correlated with feelings of anxiety. Common solutions included: easily understood information, clear explanation, and better counseling. The majority of studies reviewed suggest that with UNHS some degree of anxiety may occur. However, it is not long lasting. Two studies reported higher levels of parental anxiety, but both authors concluded that the level of stress experienced by a parents whose infant referred were to a degree that would disrupt maternal bonding due to the screening result (Yoshinaga-Itano and Gravel, 2001and Stach and Santilli, 1998).

The current study was initiated to compare parental response to UNHS across three levels of nurseries, well-baby (WBN), special care (SCN), and neonatal intensive care unit (NICU). The goal of this study was to obtain information that will assist clinicians in educating parents on the results of hearing screening, in a way that minimizes stress and anxiety. The questionnaire included questions concerning emotional response to screening, response to verbal versus written explanation of results, the professional delivery results, and optimal time for screening.

Methods

SUBJECTS

Parents of 120 infants from three levels of nurseries were contacted. The nurseries were the Neonatal Intensive Care Unit (NICU) at St. Louis Children's Hospital, Barnes-Jewish South

Special Care nursery, and Barnes-Jewish Central well-baby nursery. Twenty NICU interviews, 20 Special Care interviews, and 20 Well-baby interviews were conducted with parents of infants who passed the screening. Twenty NICU interviews, 20 Special Care interviews, and 20 well-baby interviews were conducted with parents of infants who referred on the screening. In order to obtain the 120 parents for the study, attempts to contact 242 parents were made. Attrition was due to the following: 82 could not be contacted during the three-week post-screening period, 26 declined, eight did not know results, and six did not speak English.

PROCEDURES

Institutional Review Board approval was obtained from the Committee on Human Studies at Washington University School of Medicine. Parent/guardian names, telephone numbers, and other pertinent information were obtained from the infants' medical record with supervision of the coordinator of the UNHS program and the manager of the audiology department at St. Louis Children's Hospital. The examiner contacted parents/guardians by telephone, within one-to-three weeks of the date the hearing screening was completed. The survey script, which included nine questions, may be found in appendix A.

All participants were required to have knowledge that their infant's hearing was screened prior to discharge from the nursery. Data were included for analysis if the response to the first question "Were you aware that your baby's hearing was screened prior to his/her discharge from the hospital?" was "Yes."

Five individuals with experience performing UNHS at St. Louis Children's Hospital evaluated each response as positive, negative, neutral, or unclassifiable. In order for a response to be classified, three of the five individuals had to rate the response the same way. If parents/guardians provided multiple responses, all responses were accepted.

RESULTS

Sixty-six (55%) of the infants were male and 53 (45%) were female. Of the 120 parents completing the survey 105 (88%) were mothers and 15 (13%) were fathers.

Pass Analysis

For 60 infants who passed the screening, 55 mothers and five fathers completed the survey. Figure 5 lists the initial emotional response reported by the parents at the time of the hearing screening. Figure 6 lists the emotional responses reported by parents from one to three weeks after the initial screening. All responses are listed in figures 5-8.

Across all nurseries, those who passed the hearing screening reported positive emotions at the time of the screening 92% (N=69) of the time negative emotions four percent (N=3) of the time and neutral responses three percent (N=2) of the time. One emotional response could not be classified. Classification of emotional responses can be found in figures 1-4.

Across all nurseries, those who passed the hearing screening reported positive emotions one-to-three weeks after the screening 87% (N=67) of the time. At this time, zero percent (N=0) of the emotional responses were negative and 13% (N=10) of responses were neutral.

Figure 9 depicts the method used to inform parents of their infant's hearing screening results. Parents in all three nurseries were either informed through a verbal explanation, a written explanation or in some cases verbal/written (V/W). The most common mode of explanation was verbal for the SC nursery (50% N=10) and the NICU (50% N=10). However, verbal (45% N=9) and written (45% N=9) explanations were equally as common for the WB nursery. Although all nurseries utilize all three modes of explanation, the well-baby nursery is more likely to rely on written explanation alone.

Figure 10 depicts which professional explained the results, if a verbal explanation was used. If the parent was able to report who performed the screening, the nurse was named most often as the professional who informed the parent of the passing result (WBN 33 % N=3, SCN 45% N=9, and NICU 80% N=11). It is important to note that in the well-baby nursery the majority of parents (67% N=6) could not remember who performed the screening. The physician was the second most prevalent informer in the special care nursery (10% N=2) and NICU (12% N=2). The screener was the third most common response in these two nurseries.

Figure 11 shows whether or not the parent thought the mode of explanation they received was easy to understand. Explanations could be verbal only, written only, or verbal/written. The written explanation of UNHS results can be found as Appendix D. Results revealed similar findings across all nurseries. Across all nurseries verbal explanations were unanimously rated as easy to understand. In the well-baby and special care nurseries all three forms of explanation were unanimously rated as easy to understand. In the NICU the written (75% N=3) and verbal/written (83% N=5) explanations were rated as easy to understand in a majority of cases. It must also be noted that in many of the interviews, parents reported simply getting an explanation that consisted of "the UNHS was done, your baby passed."

Figure 12 illustrates responses to the question "Who do you think is the best professional to discuss hearing screening results with you?" It must be noted that the data on this question reflects the parent's option to indicate more than one professional in response to this question. Well-baby and NICU parents reported wanting a physician (WBN 38% N= 9 and NICU 46% N=13) to explain the results. Other professionals commonly listed in the well-baby and NICU were a nurse (WBN 29 N=7 and NICU 21% N=6) or the screener (WB 21% N=5 and NICU 2% N=6) to explain the results.

In the special care nursery parents equally report wanting the nurse (29% N=7) or screener (29% N=7) to explain the results, with physician (25% N=6) ranking third.

Figure 13 depicts responses with respect to the time when parents felt it was best to screen hearing. Parents were given the opportunity to select from three choices: 1) in the nursery prior to discharge, 2) at the first well-baby check with your primary care physician, or 3) other. Parents were allowed to respond with more than one choice in response to this question, as reflected in the data. The choice of screening the hearing in the nursery prior to discharge was chosen by a high percentage of parents across all nurseries (WBN 70% N=14, SCN 85% N=17, and NICU 80% N=16).

The last question posed to the parents was "What recommendations do you have for the hearing screening coordinator to improve the program?" Common themes were noted by the examiner (See Appendix C for actual parent responses).

Refer Analysis

For all infants who referred on the screening, 50 mother and ten fathers completed the survey. Classification of all responses can be found in figures 1-4. Figure 7 lists the initial emotional response reported by the parents at the time of the hearing screening. Figure 8 lists the emotional responses reported by the parents from one-to-three weeks after the initial screening.

Across all nurseries, those who referred on the hearing screening reported positive emotions at the time of the screening 34% (N=32) of the time. At this time, 52% (N=49) of the emotional responses were negative and nine percent (N=8) of responses were neutral. Five responses could not be classified.

Across all nurseries for those whose infants referred on the hearing screening, parents reported positive emotions one-to-three weeks after the initial screening 57% (N=48) of the time.

At this time, 19% (N=16) of the emotional responses were negative and 21% (N=18) of responses were neutral. Three emotional responses could not be classified.

Figure 9 depicts the method used to inform parents of their infant's hearing screening results. Parents in all three nurseries were either informed through a verbal explanation, a written explanation or in some cases both written and verbal. Across all three nurseries the majority of explanations were verbal (WBN 50% N= 10, SCN 70% N=14, and NICU 65% N=13). Although all nurseries utilize all three modes of explanation, the well-baby nursery is more likely to rely on written explanation alone.

Figure 10 depicts which professional explained the results, if a verbal explanation was used. The professionals most often giving the results, if the parent could remember, included nurses (SCN 28% N= 5 and NICU 30%, N=6) and screeners (SCN 33% N= 6 and NICU 25% N=5) in the special care nursery and NICU. In the well-baby nursery the most frequent response was, "I do not remember." (39% N=7), followed by the nurse (28% N=5).

Figure 11 shows whether or not the parent thought the explanation was easy to understand. The explanation came in three forms, verbal only, written only, and verbal/written. The majority of parent found whatever mode of explanation they received to be easy to understand (90% N=106). The largest percentage of parents who reported that the explanation they received was not easy to understand came from the well-baby nursery. Across type of explanations 35% (N=7) of parents reported the explanation was not easy to understand (SCN 5% N=1 and NICU 10% N=2). In the Special Care (N=14) and NICU (N=13) nurseries 100% of the verbal explanations were easily understood. Parents from the well-baby nursery reported the verbal explanation was easy to understand 70% (N=7) of the time. When verbal/written explanation were given 100% of parents from the special care nurseries (N=3) reported that the

explanation was easy to understand. Across nurseries written only explanations were understood easily in the WBN 67% (N=2) of the time, SCN 67% of the time (N=1), and NICU 50% of the time (N=1).

Figure 12 illustrates responses to the question "Who do you think is the best professional to discuss hearing screening results with you?" It must be noted that the data on this question reflects the parent's option to indicate more than one professional in response to this question. In most cases, parents want a physician (WBN 55% N=12, SCN 62% N=13, and NICU 46% N=13) to be responsible for explanation of results. The screener was the second most common response across all nurseries (WBN 18 % N=4, SCN 14% N=3, and NICU 25% N=7). Nurses were the third most common response in the Well baby (14% N=3) and Special Care (10% N=2) nurseries while the audiologist came in third in the NICU (11% N=3).

Figure 13 depicts responses with respect to the time when parents felt it was best to screen their infants' hearing. The alternatives provided were as follows: 1) in the nursery prior to discharge, 2) at the first well-baby check with your primary care physician, and 3) other. The data include multiple responses given by some participants. The choice of screening prior to discharge was the most common (WBN 50% N=12, SCN 60% N=12, and NICU 45% N=10). The choice of being screened at the first well-baby check with the primary care physician was selected as follows: WBN 25% N=6, SCN 20% N=4, and NICU 32% N=7. The choice of "other" was chosen in some instances (22% N=14).

The last question posed to the parents was "What recommendations do you have for the hearing screening coordinator to improve the program?" Parents suggested that the professionals check the babies' ears before screening. A full explanation of the screening and possible reasons for the refer was also requested, and finally, parents want to be present for screening and want to

know in detail what the screening is doing and what the results mean. Verbatim comments can be found in appendix C.

Discussion

The current study questions regarding emotional reaction at the time of the screening and emotional reaction at the time of the interview were posed in an open-ended manner. This resulted in a number of responses that did not classify as emotions/feelings in a strict sense. In some of the research previously conducted, authors note exact emotions felt by the parents (deUzcategui & Yoshinaga-Itano, 1997 and Sorenson et al, 1984). The methods used to obtain emotional reactions in these studies were not specified. The authors do not report whether the surveys were open-ended or whether a closed set of responses was given. Other research states that forced-choice questions were utilized and the responses were classified by a set criterion (Watkins et al, 1998; Stuart et al, 2000; Vohr et al, 2001; Weichbold et al, 2001; Weichbold et al, 2001).

In this study the first question the parents were asked was, "What emotions did you feel when you received the results of the hearing screening?" Followed by, "What emotions do you feel now regarding the results of the hearing screening?" In regard to the differences in emotional responses between the pass and refer participants, pass participants reported a much larger percentage of positive emotions (84% N=69) compared to the parents of infants who referred (34% N=32) at the time of the hearing screening. Although there were a variety of negative responses given by the parents (see figures 5-8, "concern" (12% N=22) and "worried" (9% N=9) were the most common. These two negative responses were similar across the three levels of nurseries. This outcome was not unexpected. The theme of the UNHS at the participating hospitals, St. Louis Children's Hospital and Barnes Hospital, is "concern and return". Concern

was the most common emotion expressed for the refer participants, which may indicate that these parents are being counseled appropriately so that they realize the importance of returning for further testing to rule out hearing loss. With respect to "worry," the study did not probe to determine whether the level of worry was mild, moderate, or severe.

Parental emotional responses compared between the time of the hearing screening and at the time of the survey (one to three weeks post screening) yielded an unanticipated outcome. Overall, pass participants continued to report more positive emotions (87% N=67) compared to refer participants (57% N=48) one-to-three weeks later. Although, the emotional responses of the refer participants became more positive after one to three weeks (57%) compared to their initial emotional responses from the time of the screening (34%). Watkin et al (1998) reported a similar trend in parental responses becoming less "worried" over time. These authors reported that 59% of parents reported some degree of worry after the initial screening. Forty-two percent of parents who were initially worried continued to report worry at the re-screening. Clemens et al (2000) reported that only 14% of parents reported any degree of residual anxiety after their infant passed a follow-up screening. The study found that although initial anxiety is common, it dissipates quickly after the infant passed a stage two screening.

The author speculates that an explanation for the decreased degree of "worry" over time is due to a natural human response. Any time people are given important information, positive or negative, their initial reaction is more emotionally charged than their reaction to the information at a later time. In the case of a refer on UNHS, parents are immediately very worried or concerned and have many unanswered questions. As their questions get answered and they have time to work through their emotions regarding the information their emotional reaction lessens. Another plausible explanation for decreased "worry" is that the parents had been in contact with

the pediatrician and received further counseling. It is highly probable that the parents of infants across nurseries were in contact with their pediatrician within the first three weeks following hospital discharge. The pediatricians may have eased some of their negatively charged emotions.

When comparing emotional responses across nurseries no particular trend was noted that could not be accounted for by differences in pass versus refer screening results. In all nurseries, at the time of the screening, pass participants noted a greater percentage of positive responses (84%) while refer participants reported a larger percentage of negative responses (52%). The author had speculated that parents of infants cared for in the well-baby nursery would have a greater percentage of negative emotions associated with a refer at the time of the hearing screening than parents of infants cared for in the special care nursery or NICU. This speculation was based on the belief that parents of well-baby infants would not be as prepared for "bad news" about their infant as parents who had already received other alarming test results or diagnoses. The data in this study did not support this speculation. Fifty percent of well-babies who referred reported negative emotions while 50% of special care refers and 58% of NICU refers reported negative emotions at the time of the screening.

According to Sutten et al (1994), although parents' negative emotions have not typically to a degree that interferes with infant-parent bonding, some degree of worry is to be expected in parents whose infant refers. The current study found this phenomenon to hold true. This finding could serve a beneficial purpose assuming the goal of the hearing screening program is to elicit enough concern in parents whose infant refers to cause the parent to follow-up with diagnostic testing. The degree of concern experienced by these parents is positive in that it encourages them to schedule and attend follow-up testing appointments.

Although this study did not ask a particular question to analyze how many parents were aware of the hearing screening brochure and how many parents could readily interpret this information as useful, it is interesting to note that 16 parents had unanswered questions about the screening procedure results and 10% responded that they did not easily understand the information that they were given. In addition, eight parents (3%) were unaware the screening took place. This finding supports Watkin et al (1998) and Magnuson and Hergils (1999) data. Watkin et al (1998) found that although no mothers commented on being worried due to a lack of information; over one-third reported not reading the information they were given.

In the current study the author believes that lack of awareness of the hearing screening can at least be partially explained by the overwhelming amount of information the parent received upon admission and in part by the fact that the hearing screening brochure does not in any way stand out from any of the other materials. Other studies have documented that the amount of information given to mothers directly before delivering a baby is overwhelming and is often overlooked (Magnuson et al, 1999). Magnuson et al (1999) found that 50% of parents did not remember receiving the hearing-screening brochure they were given upon admission. The most common response for why they could not remember the brochure was; "there were so many other things around."

Each nursery included in this study provides expectant mothers with an admission packet of materials upon entry to the maternity ward. Each nursery provides the same brochure on the state of Missouri's hearing screening program within this admission packet refer to Appendixes E and F for copies of these documents. There are a total of four forms stapled to the front of a booklet entitled Mother and Baby Care Book plus an additional six brochures and forms stuffed inside the booklet included in the packet mother's of infants in the well-baby nursery and special

care nursery receive. The documents cover everything from Does your Child have a legal father to the formal hospital release of medical information form to forms needed to apply for a birth certificate. Of the total 11 pieces of information, the newborn hearing screening information is a single, blue sheet of paper (Appendix E). The packet given to mothers of NICU infants is less dense. It includes a three page NICU information sheet with two brochures one entitled "Helping our Parents Envision Life Beyond the NICU" and "Universal Newborn Hearing Screening Parent Information" as well as a Children's Hospital business card stapled to the front (Appendix F). With the commotion of the delivery process and the amount of information the mother has to digest, it comes as no surprise that the information on UNHS is not read immediately.

It is clear by the responses obtained to the question "Was the verbal/written explanation easy to understand?" that a verbal explanation of UNHS results is more readily understandable than written, across nurseries and pass and refer results. In conjunction with the percentage of parents finding the verbal explanation easy to understand, comes the number of total instances a verbal only explanation was utilized across situations and nurseries. Verbal only explanation was utilized more in both situations (pass and refer), across nurseries. Although all nurseries utilize all three modes of explanation, the well-baby nursery with a pass result, is the only situation that relies on written explanations as often as verbal explanations.

Overall, 90% of parents found the explanation, verbal, written, or in combination easy to understand. Of the 66 total verbal only explanations, only five percent (N=3) of parents reported that they found the explanation difficult to understand. These results suggest that those professionals currently verbally counseling parents on the results of UNHS are sufficiently trained to relay the information and answer questions parents have in a manner that is acceptable

to the parents. Since eight percent of parents had difficulty understanding the written and verbal plus written results suggests that there is room for improvement in the counseling of parents on UNHS.

When asked, "Who do you think is the best professional to discuss hearing screening results with you?" 45% of parents expressed a desire to have a physician deliver the screening results. The author believes that parents associate a level of trust in a physician, and in turn believe they are the most competent to relay the results of the hearing screening. This information is interesting because physicians provided results in only 17% of all cases. For those who chose other professionals, the researcher noted in many cases that these professionals were chosen out of experience. For example, of parents who did not indicate a doctor should provide the results, 21% chose the screener. The screener performed the screening in 22% of cases. In these cases, it appears that the parents are satisfied with the performance of the person who performed the screening. The level of the nursery and the result obtained did not seem to influence the parental choice of the health care provider desired for delivering results.

According to the UNHS coordinator, physicians are not the most appropriate professionals to relay the results to parents for a number of reasons. One reason is that physicians are not assessable in the maternity unit in a way that would ensure timely delivery of results to the parent. Nurses are present 100% of the time during an infant's stay in the nursery and are more familiar with the infant and the mother; they come in contact much more frequently than do the parent/infant and physician once delivery is complete. In the current study setting training physicians to counsel would be inefficient. The study was carried out in a university teaching hospital where physicians are on constantly changing rotations from department to department. It is not cost effective for the audiology coordinator to train new physicians every six-to-eight

weeks when nurses are capable of delivering and explaining the results. Also, given the hierarchy there is little recourse if a physician's performance is below standards. The coordinator believes that the UNHS program can be held to higher standards if the professionals relaying results are under the supervision of the audiology department.

The second choice of parents was the nurse in the well-baby and special-care nurseries. In the NICU the second choice was the audiologist. As with physicians, parents get to know their nurses during their hospital stay, and a level of trust is developed between the parent and the nurse. In the NICU, with more involved factors complicating an infant's hospitalization, the parents typically becomes more knowledgeable about different professionals and their role in health care needs. It is possible that this higher level of education on the part of the parents is the reason that NICU parents chose the audiologist over nurses to explain UNHS.

Parents were asked to choose between screening in the nursery prior to discharge, at the first well-baby check with the primary care physician, or sometime other than these two previous choices. In general, participants had a clear preference for screening before discharge across all nurseries. This suggests that the parents were satisfied with their experiences when the screening was performed in the nursery prior to discharge. Even though the majority of all parents indicated that they were happy with screening prior to discharge, the refer participants' had more divergent responses across all three nurseries. When refer participants' responses are compared to the pass participants, it is evident that parents of infants who referred on the screening choose at the first well-baby check (15%) or times other than in the hospital nursery (12%) more often than parents whose infant passed on the screening completed before hospital discharge (3% at first well-baby check-up, 3% other). This occurrence is most likely due to the parent's experience. When the infant fails a screening, parents are given a list of possible explanations that could account for the

result, several of which suggest that later the infant may pass a re-screening. Examples of these types of possible refer explanations are vernix remaining in the ear canal, fluid in the middle ear space, and immature nervous system. Given these explanations, the parent may think that a later screening would decrease the likelihood of a false positive. Another possible explanation may be due to the fact that a trusted and reassuring professional, such as the pediatrician, would be performing the screening.

Of all the parents who did not believe UNHS should be performed before hospital discharge, 17% (N=20) chose the first well-baby check as an appropriate time for screening. Fourteen percent (N=17) of parents chose "Other." If the infant referred 27% said it should be done at a different time. In contrast, if the infants passed six percent of the parents did not believe UNHS should be done in the nursery. Common suggestions given by parents who reported "Other" as the most appropriate time to screen hearing include: "Anytime" (N=3), "Whenever possible" (N=2), "Whenever the professional deems necessary" (N=1), "At twelve months" (N=1), "After one year" (N=1), "Within one month" (N=1), "No specific time" (N=1), "ASAP" (N=1) and "At two months" (N=1). Magnuson and Hergils (1999) reported that two parents (4%) preferred screening to be performed at two weeks of age, rather than screening before discharge. Both of these parents had infant's who referred on the initial screening. This type of response suggests the need for further education by hearing professionals, pediatricians, nurses, and possibly even pre-natal classes and books.

It is prescribed by law that initial screenings must occur in the hospital prior to discharge. The law was written to perform UNHS before hospital discharge in order to obtain the highest capture rate, not to optimize refer rates or accommodate parent schedule. The first well-baby check-up with the primary care physician may in fact be a more appropriate time to screen infants

for hearing loss from a timing perspective. Literature suggests that screenings are more valid during the first seven to ten days of a baby's life than within 24 hours of birth. Technically, performing the initial screening sometime after hospital discharge is possible. Many hearing screening instrument manufacturers are actively marketing screening equipment to pediatricians for use in their offices. Even if the law requires initial screening prior to discharge, it may be a good idea for pediatricians to offer follow-up screenings. One possible drawback to screening in the physician's office is the level of noise present. Current otoacoustic emissions (OAE) screening equipment requires a relatively quiet environment in order to obtain accurate results.

Parents want to be notified that the UNHS will occur before the baby is discharged. Parents want to be informed about the UNHS and what it will entail. They want to know in detail how the screening works. Many parents expressed their lack of knowledge with respect to how a newborn's hearing can be screened. Parents want to know how the results were obtained and what a "Pass" actually means for the future of their child. Some of the parents in the NICU also expressed a need for being informed more quickly of the results and wanted a letter from the audiologist regarding results and an explanation. The majority of comments from parents whose infants passed the screening were positive in regards to how the screening was carried out and the information they were given. These parents said "everything was fine, nothing needs to be changed" or something to a similar effect.

Recommendations given by parents to improve hearing screening provide future direction. Parents want to be notified that the UNHS will occur; they want to be informed about the UNHS program and what is will entail. Parents want to know in detail how the screening is done and how a pass or refer is determined. Parents also want to know what the results actually mean for the future of their child. Finally, parents want to be present during the screening.

It is important to mention that in the population surveyed in this study all had their infants cared for in an urban, inner city hospital. Of the 120 parents surveyed 49% were from minority groups. It cannot be predicted if the results of this study will generalize across other communities. It is recommended that screening coordinators survey a sample of their parents periodically to ensure a high quality program.

The author would like to contribute some suggestions for future research on parental response to UNHS. If the goal of UNHS programs is "concern and return" it would be interesting to examine if those parent who are reporting higher rates of "concern" and "worry" in regard to screening results are following-up with diagnostic testing at a higher rate than parents who express less "concern" or "worry." Another area of interest is the design of the questions regarding emotional responses. In this study, the questions were open-ended to encourage parents to express their feelings/emotions in their own words and not limit the words/phrases they could use to express themselves. A design that would have probed the level (i.e. mildly worried versus very worried) of positive and negative responses after the open-set response would not have limited the parents flexibility to express their emotions. This design would have also been beneficial in the analysis of the degree of worry the parents were facing. This and other authors speculate that the rate of return does in deed correlate with the rate of "concern." This type of data would help delineate if this hypothesis is true.

Appendix A

PARENTAL RESPONSE TO NEWBORN HEARING SCREENING
PRINCIPLE INVESTIGATORS: Megan Terry, Graduate Student
Roanne Karzon, Ph.D. CCC-A

Telephone Questionnaire

Nursery_____
Survey #_____

Newborn Hearing Screening Questionnaire

*Name of Neonate:

*Name of parent/guardian(s)_____

*Phone number_____

*Phone number_____

Overall screen result: Pass_____ Refer_____

This identifying information (denotes with *) will be discarded after
1) Data is collected and completed, or
2) Parent/guardian states that they do not wish to participate, or
3) No contact is made with the parent/guardian after reasonable attempts to reach them within the time span or the study (1 to 3 weeks post-discharge).

Title: Parental Response to Newborn Hearing Screening
"Hello. My name is Megan Terry and I am calling on behalf of Dr. Karzon, the manager of the Pediatric Audiology Department at St. Louis Children's Hospital. We are calling today to see if you would like to participate in a survey about hearing screening. All newborns in Missouri have their hearing screened prior to discharge from the hospital. The screening was implemented to provide early identification of hearing loss. Would you like to participate in our survey?"

No—"Thank you for considering participation. Would you like any additional information about the hearing screening program or your baby's results?"
No—"Thank you again for your time, goodbye."
Yes—Explain, that you will have an audiologist with the screening program give them a call. Verify the phone number. "Thank you again for your time, goodbye." *Provide the name and number to either Carole Campbell or Roanne Karzon for call back.*
Yes—Continue Survey

Were you aware that your baby's hearing was screened prior to his/her discharge from the hospital?

Yes—"Thank you for your participation. Before we begin I would like to assure you that your baby's information will be kept confidential. No names will be used in any presentation of the data."

Were you aware that your baby's hearing was screened in the nursery before leaving the hospital?
No—Thank you for considering participation. Would you like any additional information about the hearing screening program or your baby's results?
No—"Thank you again for your time, goodbye."
Yes—Explain, that you will have an audiologist with the screening program give them a call. Verify the phone number. "Thank you again for your time, goodbye." *Provide the name and number to either Carole Campbell or Roanne Karzon for call back.*

Yes—Continue Survey

"Thank you for your participation. To complete the study in compliance with the Health Insurance and Portability Act, I need to share some information with you. Your baby's hearing screening information was obtained through Carole Campbell, the coordinator of the Infant Hearing Screening Programs at Barnes-Jewish Hospital South and St. Louis Children's Hospital. She works closely with Dr. Karzon, the manager of the Pediatric Audiology Department. Your baby's information will be kept confidential. No names will be used in any presentation of data. At the conclusion of this phone call, I will discard the names and phone numbers from the research papers. All of our data is used in a group format and cannot be traced to a particular infant or family. You may conclude this phone call at any time. Participation will not affect any health care decisions.

According to the Health Insurance and Portability Act I must make you aware of the Joint Notice of Privacy Practices, a document that describes how medical information about you and your baby may be used and disclosed and how you can access this information. If you would like more information about this document I can have it mailed to you, give you a web address where it is located, or give you a telephone number to contact a representative that will be able to answer questions you may have. Would you like further information concerning this document?

No—Continue Survey
Yes—I can have this document sent to you through standard mail, give you a telephone number you can call and have any questions you have about this document answered for you, or a website you can access it on. Which method would you prefer?

--Mail- Obtain mailing address (Written directly on envelope)
--Website- WWW.BJC.ORG
--Phone- (314) TOP-DOCS

What emotions did you feel when you received the results of the hearing screening?

_____ _____ _____

_____ _____ _____

What emotions do you feel now regarding the hearing screening results of your infant?

_____ _____ _____

_____ _____ _____

Did you receive the results first in writing or verbally? Verbal _____written_____

If verbal---who explained the results? (Name/and or title)_____

Was the verbal explanation easy to understand? Yes_____ No_____

If written---was the written explanation easy to understand? Yes_____ No_____

Who do you think is the best professional to discuss hearing screening results with you?

_____

When do you think would be the best time to screen hearing?

_____in the nursery prior to discharge

_____ at the first well-baby check with the primary care physician.

_____ other (specify)_____

What recommendations do you have for the hearing screening coordinator to improve the program?

_____

_____

We would like to record the following information from your baby's Medical Record. Please say yes for each of the items for which you grant permission:

Yes No EGA
Yes No Date of birth
Yes No Gender
Yes No Ethnicity
Yes No Date of Discharge
Yes No Date of hearing screening
Yes No Result of Screening- Pass_____

Refer Unilateral_____ Level _____
Refer bilateral_____ Right level_____ Left level_____

Yes No Discharge Diagnoses:

_____ _____ _____

_____ _____ _____

Those items that have a yes will be obtained from the medical record.

We really appreciate your participation. Would you like any additional information about the hearing screening program or your baby's results?

No—"Thank you again for your time, goodbye."

Yes—Explain, that you will have an audiologist with the screening program give them a call. Verify the phone number. "Thank you again for your time, goodbye." *Provide the name and number to either Carole Campbell or Roanne Karzon for call back.*

Appendix B

Health Insurance and Portability Act—Joint Notice of Privacy Practices

BARNES-JEWISH Hospital BJC HealthCare

Children's HOSPITAL • ST. LOUIS BJC HealthCare

Washington University in St. Louis SCHOOL OF MEDICINE

JOINT NOTICE OF PRIVACY PRACTICES

Effective Date: ***April 14, 2003***
Last Revision Date: None

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

This Notice serves as a joint notice for Barnes-Jewish Hospital, St. Louis Children's Hospital and Washington University School of Medicine (collectively referred to herein as "we" or "our"). We have designated ourselves as an organized health care arrangement under the Health Insurance Portability and Accountability Act of 1996. We will follow the terms of this Notice and may share health information with each other for purposes of treatment, payment and health care operations as described in this Notice. Since we maintain health information separately, we will respond separately to your questions, requests and complaints concerning your health information.

OUR DUTIES REGARDING YOUR HEALTH INFORMATION

We respect the confidentiality of your health information and recognize that information about your health is personal. We are committed to protecting your health information and to informing you of your rights regarding such information. We are also required by law to protect the privacy of your protected health information and to provide you with notice of these legal duties. This Notice explains how, when and why we typically use and disclose health information and your privacy rights regarding your health information. In our Notice, we refer to our uses and disclosures of health information as our "Privacy Practices." Protected health information generally includes information that we create or receive that identifies you and your past, present or future health status or care or the provision of or payment for that health care. We are obligated to abide by these Privacy Practices as of the effective date listed above.

We may, however, change our Privacy Practices in the future and specifically reserve our right to change the terms of this Notice and our Privacy Practices. We will communicate any change in our Notice and Privacy Practices as described at the end of this Notice. Any changes that we make in our Privacy Practices will affect any protected health information that we maintain.

Generally, our Privacy Practices strive:

- To make sure that health information that identifies you is kept private;
- To give you this Notice of our Privacy Practices and legal duties with respect to protected health information;
- To follow the terms of the Notice that is currently in effect; and
- To make a good faith effort to obtain from you a written acknowledgement that you have received or been given an opportunity to receive this Notice.

HEALTH CARE PROVIDERS INCLUDED IN THIS NOTICE

Our Notice serves as a Joint Notice and we will follow the terms of this Notice. This Notice, however, also describes the Privacy Practices of BJC HealthCare affiliated facilities and personnel ("BJC affiliated sites"). Specifically, our Notice also describes the Privacy Practices of:

- Any BJC HealthCare affiliated hospital and the health care professionals authorized to enter information into your hospital chart;
- All departments and units of our affiliated hospitals, including BJC Pharmacies;
- All of our employed physicians and their practice sites;
- All hospital-based physicians such as anesthesiologists, pathologists and radiologists;
- Any member of a volunteer group we allow to help you while you are receiving care from us;
- BJC Long Term Care and Senior Services, BJC Corporate Health Services, BJC Behavioral Health, BJC Home Care Services, and BJC Vision Centers;
- All employees, staff and other BJC HealthCare affiliated hospital personnel, including those employees or personnel of any other BJC HealthCare affiliated sites.

A complete listing of our general classes of service delivery sites and the affiliated BJC HealthCare sites addressed in this Notice are listed on the last page of this Notice, each of whom have agreed to follow the terms of our Notice.

Our Notice does not address the privacy practices that your personal doctor (if not employed by us) may use in his or her private office and will not affect the medical decisions they make in your care and treatment.

HOW WE MAY USE AND DISCLOSE HEALTH INFORMATION ABOUT YOU

We use and disclose your protected health information in a variety of circumstances and for different reasons. Many of these uses and disclosures require your prior authorization. There are situations, however, in which we may use and disclose your health information without your authorization. Many of these uses and disclosures will occur with your treatment, for payment of health services or for our health care operations. There are additional situations, however, where the law permits or requires us to use and disclose your health information without your authorization. These situations will also be described in this section of the Notice. Specifically, we may use and disclose your protected health information as follows:

For Treatment, Payment and Health Care Operations

1. **For Your Treatment.** We may use and/or disclose your protected health information to physicians, nurses, dietitians, technicians, residents, medical or other health professional students, physical therapists or other health care personnel who are involved in your care and who will provide you with medical treatment or services. For example, if you have had surgery or just had a baby, we may contact a home health care agency to arrange for home services or to check on your recovery after you are discharged from the hospital.

2. **For Payment of Health Services that You Receive.** We may use and/or disclose your protected health information to bill and receive payment for the health services that you receive from us. For example, we may provide your health information to our billing or claims department to prepare a bill or statement to send to your insurance company, including Medicare or Medicaid, or another group or individual that may be responsible for payment for your health services.

3. **For Our Health Care Operations.** We perform many activities to help assess and improve the services that we provide. Such activities include, among others, participating in medical or nursing training

programs or education, performing quality reviews, conducting patient opinion surveys, developing clinical guidelines and protocols, engaging in case management and care coordination, business management, insurance or legal compliance reviews or participating in accreditation surveys such as the Joint Commission for the Accreditation of Healthcare Organizations. These activities are referred to as "health care operations." We may use and/or disclose health information for purposes of any of these health care operations.

For example, we may use health information to assess the scope of our services or to determine if additional health services are needed. In determining what services are needed, we may disclose health information to physicians, medical or other health or business professionals for review, consultation, comparison and planning. If we use or disclose health information in this manner, we may try to remove any information that identifies you to further protect your health information. Additionally, we may disclose health information to auditors, accountants, attorneys, government regulators, or other consultants to assess and/or ensure our compliance with laws or to represent us before regulatory or other governing authorities or judicial bodies.

4. **For Another Provider's Treatment, Payment or Health Care Operations.** The law also permits us to disclose your protected health information to another health care provider involved with your treatment to enable that provider to treat you and get paid for those services as well as for that provider's health care operation activities involving quality reviews, assessments or compliance audits.

5. **Special Circumstances When We May Disclose Your Health Information related to Treatment, Payment or Health Care Operations.** After removing direct identifying information (such as your name, address, and social security number) from the health information, we may use your health information for research, public health activities or other health care operations (such as business planning). While only limited identifying information will be used, we will also obtain certain assurances from the recipient of such health information that they will safeguard the information and only use and disclose the information for limited purposes.

Additionally, we may disclose health information to outside organizations or providers in order for them to provide services to you on our behalf. We will also seek written assurances from these providers to safeguard the health information that they receive.

For Permitted or Required by Law Activities.

There are situations where we may use and/or disclose your health information without first obtaining your written authorization for purposes other than for treatment, payment, or health care operations. Except for the specific situations where the law requires us to use and disclose information (such as reports of births to the health department or reports of abuse or neglect to social services), we have listed all these permitted uses and disclosures in this section.

1. **For Public Health Activities.** We may use or disclose health information to a public health authority that is authorized by law to collect or receive information in order to report, among other things, communicable diseases and child abuse, or to the F.D.A. to report medical device or product related events. In certain limited situations, we may also disclose health information to notify a person exposed to a communicable disease.

2. **For Health Oversight Activities.** We may disclose health information to a health oversight agency that includes, among others, an agency of the federal or state government that is authorized by law to monitor the health care system.

3. **For Law Enforcement Activities.** We may disclose limited health information in response to a law enforcement official's request for information to identify or locate a victim, a suspect, a fugitive, a material

witness or a missing person (including individuals who have died) or for reporting a crime that has occurred on our premises or that may have caused a need for emergency services.

4. **For Judicial and Administrative Proceedings.** We may disclose health information in response to a subpoena or order of a court or administrative tribunal.

5. **To Coroners, Medical Examiners, and Funeral Directors.** We may release health information to a coroner or medical examiner to identify a deceased person or to determine the cause of death.

6. **For Purposes of Organ Donation.** We may disclose health information to an organ procurement organization or other facility that participates in the procurement, banking or transplantation of organs or tissues.

7. **For Purposes of Research.** We conduct and participate in medical, social, psychological and other types of research. Most research projects are subject to a special approval process to evaluate the proposed research project and its use of health information before we use or disclose health information. In certain circumstances, however, we may disclose health information to people preparing to conduct a research project to help them determine whether a research project can be carried out or will be useful, so long as the health information they review does not leave our premises.

Additionally, because we are committed to advancing science and medicine, and as a part of your treatment, our clinicians may offer you information about clinical research trials (investigational treatments). To determine whether you are a candidate for certain clinical trials, our clinicians and research personnel may occasionally review your medical records and compare your information to the clinical trial requirements.

8. **To Avoid Harm to a Person or for Public Safety.** We may use and disclose health information if we believe that the disclosure is necessary to prevent or lessen a serious threat or harm to the public or the health or safety of another person.

9. **For Specialized Government Functions.** We may use and disclose health information of certain military individuals, for specific governmental security needs, or as needed by correctional institutions.

10. **For Workers' Compensation Purposes.** We may disclose your health information to comply with the workers' compensation laws or other similar programs.

11. **For Appointment Reminders and to Inform You of Health Related Products or Services.** We may use or disclose your health information to contact you for medical appointments or other scheduled services, or to provide you with information about treatment alternatives or other health-related products and services.

12. **For Fund-raising Purposes.** We may use or disclose demographic information, including the dates that you received health care from us, to contact you to raise funds for us to continue or expand our health care activities. If you do not wish to be contacted as part of our fund-raising efforts, please contact the individual(s) listed in the Contact Section of this Notice.

When your preferences will guide our use or disclosure.

While the law permits certain uses and disclosures without your authorization, the law also provides you with an opportunity to inform us of your preference, in certain limited situations, concerning the use or disclosure of your health information. For these limited uses and disclosures, we may simply ask and you may simply tell us your preference concerning the use or disclosure of your health information. These limited situations include:

1. Facility directory information on individuals who are receiving health services from us. A facility directory may include your name, your location in the facility, your general condition such as fair, stable, etc., and your religious affiliation (if provided by you). Unless you tell us that you would like to restrict

your information in a facility directory, you will be included and directory information may be disclosed to members of the clergy or to people who ask for you by name.

2. The information, if any, given to family or friends. Unless you tell us otherwise prior to a discussion or if your situation appears to permit us, we may disclose to a family member, other relative or a close personal friend health information concerning your care, including information concerning the payment for your care.

All Other Uses and Disclosures Require Your Prior Written Authorization.

For situations not generally described in our Notice, we will ask for your written authorization before we use or disclose your health information. You may revoke that authorization, in writing, at any time to stop future disclosures of your information. Information previously disclosed, however, will not be requested to be returned nor will your revocation affect any action that we have already taken. In addition, if we collected the information in connection with a research study, we are permitted to use and disclose that information to the extent it is necessary to protect the integrity of the research study.

YOUR RIGHTS REGARDING YOUR HEALTH INFORMATION

This portion of our Notice describes your individual privacy rights regarding your health information and how you may exercise those rights.

Requesting Restrictions of Certain Uses and Disclosures of Health Information.

You may request, in writing, a restriction on how we use or disclose your protected health information for your treatment, for payment of your health care services, or for activities related to our health care operations. You may also request a restriction on what health information we may disclose to someone who is involved in your care, such as a family member or friend To make a request to Washington University, please contact the individual listed in the Contact Section of this Notice. For hospitals or BJC affiliated sites, please contact the medical records department or other designated department that maintains your health information.

We are not required to agree to your request. Additionally, any restriction that we may approve will not affect any use or disclosure that we are legally required or permitted to make under the law, including our facility directory.

Requesting Confidential Communications.

You may request and receive reasonable changes in the manner or the location where we may contact you for appointment reminders, lab results or other related information. You must make your request in writing and specify the alternate method or location where you wish to be contacted and how you will handle payment for your health services. To make a request to Washington University, please contact the individual listed in the Contact Section of this Notice. For hospitals or BJC affiliated sites, please contact the medical records department or other designated department that maintains your health information. We will accommodate your reasonable request, but in determining whether your request is reasonable, we may consider the administrative difficulty it may impose on us.

Inspecting and Obtaining Copies of Your Health Information.

You may ask to look at and obtain a copy of your health information. You must make your request in writing. For Washington University, please submit your request to the individual listed in the Contact Section of this Notice. For hospitals or BJC affiliated sites, please submit your request to the medical records department or other designated department that maintains your health information. For instance, if you would like to view your records from your surgery at Barnes-Jewish Hospital and the related physician office records, you must submit a request at both Barnes-Jewish Hospital and your physician's office.

We may charge a fee for copying or preparing a summary of requested health information. We will respond to your request for health information within 30 days of receiving your request unless your health information is not readily accessible or the information is maintained in an off-site storage location.

Requesting a Change in Your Health Information.

You may request, in writing, a change or addition to your health information. To make a request to Washington University, please submit your request to the individual listed in the Contact Section of this Notice. For hospitals or other BJC affiliated sites, please submit your request to the medical records department or other designated department that maintains your health information. The law limits your ability to change or add to your health information. These limitations include whether we created or include the health information within our medical records or if we believe that the health information is accurate and complete without any changes. Under no circumstances will we erase or otherwise delete original documentation in your health information.

Requesting an Accounting of Disclosures of Your Health Information.

You may ask, in writing, for an accounting of certain types of disclosures of your health information. The law excludes from an accounting many of the typical disclosures, such as those made to care for you, to pay for your health services, or where you provided your written authorization to the disclosure.

To make a request for an accounting: for Washington University, please submit your request to the individual listed in the Contact Section of this Notice; for hospitals or other BJC affiliated sites, please submit your request to the medical records department or other designated department that maintains your health information. Generally, we will respond to your request within 60 days of receiving your request unless we need additional time.

Obtaining a Notice of Our Privacy Practices.

We provide you with our Notice to explain and inform you of our Privacy Practices. You may also take a copy of this Notice with you. Even if you have requested this Notice electronically, you may request a paper copy at any time. You may also view or obtain a copy of this Notice at our websites:

www.bjc.org and www.WUPhysicians.wustl.edu

CHANGES TO THIS NOTICE

We reserve the right to change this Notice concerning our Privacy Practices affecting all the health information that we now maintain, as well as information that we may receive in the future. We will provide you with the revised Notice by making it available to you upon request and by posting it at our service sites. We will also post the revised Notice on our websites.

COMPLAINTS

We welcome an opportunity to address any concerns that you may have regarding the privacy of your health information. If you believe that the privacy of your health information has been violated, you may file a complaint with the individual(s) listed in Section VII of this Notice. You also may file a complaint with the Secretary of the U.S. Department of Health and Human Services.

YOU WILL NOT BE PENALIZED OR RETALIATED AGAINST FOR FILING A COMPLAINT.

CONTACT PERSONS

It is important to note that requests made to Barnes-Jewish Hospital, St. Louis Children's Hospital and Washington University must be made separately. Any requests or complaints to one provider will not be deemed to be filed with any of the other providers covered by or addressed in this Joint Notice.

For questions, concerns, requests or complaints concerning Barnes-Jewish Hospital or St. Louis Children's Hospital, you may contact the Patient Advocate/Representative who will assist you by contacting the Barnes-Jewish Hospital or St. Louis Children's Hospital Operator at the telephone number listed below and requesting the patient advocate or patient representative or by writing to the patient advocate or patient representative at the address shown below.

For questions, concerns, requests or complaints concerning Washington University or its providers, you may contact the Privacy Officer at the telephone number or address listed below. To look at or obtain a copy of your health information from a Washington University physician or provider, you may contact the Washington University physician or provider currently treating you. If you cannot contact your Washington University physician or provider or if you want to look at or obtain a copy of your health information from more than one Washington University physician or provider, you may contact the Washington University Privacy Officer at the telephone number or address listed below.

Barnes-Jewish Hospital
Patient Advocate/Patient Representative

Address: Attn: Guest and Patient Relations
Mail Stop: 90-35-711
216 S. Kingshighway
St. Louis, MO 63110

Telephone Number: (314) 362-5196

St. Louis Children's Hospital
Patient Advocate/Patient Representative

Address: Attn: Guest Relations Specialist
600 S. Taylor, 2nd Floor
St. Louis, MO 63110

Telephone Number: (314) 286-0711

Washington University
Privacy Officer

Address: Campus Box 8098
660 S. Euclid Ave.
St. Louis, MO 63110

Telephone Number: 1-866-747-4975

BJC HEALTHCARE

SERVICE DELIVERY SITES

BJC HealthCare Hospitals

Alton Memorial Hospital

Barnes-Jewish Hospital

Barnes-Jewish St. Peters Hospital

Barnes-Jewish West County Hospital

Boone Hospital Center

Christian Hospital Northeast/Northwest

Fayette County Hospital

Missouri Baptist Medical Center

Missouri Baptist Hospital - Sullivan

Parkland Health Center - Bonne Terre

Parkland Health Center - Farmington

St. Louis Children's Hospital

BJC HealthCare Long Term Care Facilities

Barnes-Jewish Extended Care, Village North Manor, Village North Health Center, and Village North Retirement Community, Eunice Smith Nursing Home, Fayette County Hospital Long Term Care

BJC Ancillary Services Providers (such as radiology, pain management or imaging services)

BJC Behavioral Health

BJC Corporate Health

BJC Home Care Services and Boone Hospital Center's Visiting Nurses

BJC Medical Group Offices

BJC Retail Pharmacies

BJC Vision Centers

Fairview Heights Medical Group

Heart Care Institute

For more information concerning BJC HealthCare facility locations, please visit our website at www.bjc.org or call 314-TOP-DOCS (314-867-3627).

Appendix C

Parental responses to the question "What recommendations do you have for the hearing screening coordinator to improve the program?"

Well-Baby—PASS

"Explain the test procedure better."

"Explain what okay means."

Special Care—PASS

"A paperwork explanation would be nice."

"This is a great idea to do at this time."

"They seem to be doing a great job."

"I was satisfied with the procedure."

NICU Nursery—PASS

"Make sure the parents are aware that the baby will be screened prior to the procedure."

"We need more information; explain how the hearing screening is done step by step so that a person not in the profession can understand what is going on."

"A letter from the audiologist regarding the results and an explanation of the results given before discharge."

"Explaining the test and how it is done would be helpful."

"I would like information and notification prior to the hearing screening."

"There seemed to be a communication gap; I had to hunt for the answers to the test."

"They seemed to do a really good job."

"I thought all went fine."

Well Baby Nursery—REFER

"They need to give a more straight forward explanation of the test."

"They should give more explanation of the test and the procedure."

"The test should be done at a different time."

"I think they should give the right amount of information so moms aren't confused and give a reason for the refer."

"Do it at the first well baby check-up."

"Explain the paper better because I'm still worried about my baby's other ear they didn't tell me what this could mean about it."

Special Care Nursery—REFER

"The parent needs more accurate information, more explanation of how the test was done, and why the baby may have failed—possible reasons."

"I don't feel I am familiar enough with the program to suggest recommendations."

"I was satisfied with the hearing screening program."

NICU Nursery—REFER

"Check the baby's ears to make sure they are clear and make sure no there is no ear infection."

"Explain every tiny detail of what is going on and what is being done."

"I was pleased with the program."

"I felt the testing process was efficient."

"I thought they did a good job."

"I was impressed with the program."

"They should wait (to screen) if the baby has recently had a procedure that could affect the test."

Figure 1.

NOTE: Classification of emotions reported by parents of infants who passed the screening when asked, "What emotions did you feel when you received the results of the hearing screening?"

	Positive		**Negative**		**Neutral**		**Unclassifiable**	
	N=	%	N=	%	N=	%	N=	%
All Nurseries	69	84%	3	4%	2	3%	1	1%
WBN	22	92%			2	8%		
SCN	25	93%	1	4%			1	4%
NICU	22	92%	2	8%				

Figure 2.

NOTE: Classification of emotions reported by parents of infants who passed the screening when asked, "What emotions do you feel now (1-3 weeks following the screening) regarding the hearing screening results of your infant?"

	Positive		**Negative**		**Neutral**		**Unclassifiable**	
	N=	%	N=	%	N=	%	N=	%
All Nurseries	67	87%			10	1%		
WBN	21	72%			8	28%		
SCN	24	96%			1	4%		
NICU	22	96%			1	4%		

Figure 3.

NOTE: Classification of emotions reported by parents of infants who referred on the screening when asked, "What emotions did you feel when you received the results of the hearing screening?"

	Positive		**Negative**		**Neutral**		**Unclassifiable**	
	N=	%	N=	%	N=	%	N=	%
All Nurseries	32	34%	49	52%	8	9%	5	5%
WBN	14	35%	20	50%	4	10%	2	5%
SCN	11	39%	14	50%	2	7%	1	4%
NICU	7	27%	15	58%	2	8%	2	8%

Figure 4.

NOTE: Classification of emotions reported by parents of infants who referred on the screening when asked, "What emotions do you feel now (1-3 weeks following the screening) regarding the hearing screening results of your infant?"

	Positive		**Negative**		**Neutral**		**Unclassifiable**	
	N=	%	N=	%	N=	%	N=	%
All Nurseries	48	57%	16	19%	18	21%	3	4%
WBN	14	42%	7	21%	11	33%	1	3%
SCN	18	64%	5	18%	4	14%	1	4%
NICU	16	67%	4	17%	3	11%	1	4 %

Figure 5.

NOTE: All emotions reported by parents of infants who passed the screening when asked, "What emotions did you feel when you received the results of the hearing screening?"

	Combined Nurseries Response	N=		Well Baby Response	N=		Special Care Response	N=		NICU Response	N=
Positive	Happy	17	**Positive**	Happy	7	**Positive**	Happy	4	**Positive**	Happy	6
	Glad	14		Glad	2		Glad	8		Glad	4
	Fine	10		Fine	3		Fine	5		Fine	2
	OK	5		OK	3		OK	1		OK	1
	Relieved	5		Relieved	1		Pleased	1		Relieved	4
	Good	4		Good	2		Calmed anxiousness	1		Good	2
	Pleased	3		Pleased	1		Comforted	1		Pleased	1
	Not worried	2		Not worried	1		Great	1		Not worried	1
	Reassured	1		Reassured	1		Interested	1		Average	1
	Very Happy	1		Very Happy	1		Relieved test was done	1			
	Calmed anxiousness	1					Satisfied	1			
	Comforted	1									
	Great	1									
	Interested	1									
	Relieved test was done	1									
	Satisfied	1									
	Average	1									
Negative	Scared before the test	2							**Negative**	Scared before screening	2
Neutral	No feelings	2	**Neutral**	No Feelings	2	**Neutral**	Anxious before test	1			
	Anxious before test	1									
Unclassifiable	Expected it to be normal	1				**Unclassifiable**	Expected result to be normal	1			

Figure 6.

NOTE: All emotions reported by parents of infants who passed the screening when asked, "What emotions do you feel now (1-3 weeks following the screening) regarding the hearing screening results of your infant?"

	Combined Nurseries Response	N=		Well Baby Response	N=		Special Care Response	N=		NICU Response	N=
Positive	Happy	16	**Positive**	Happy	7	**Positive**	Happy	3	**Positive**	Happy	6
	Glad	14		Glad	2		Glad	6		Glad	6
	Fine	8		Fine	3		Fine	3		Fine	2
	Good	8		Good	2		Good	3		Good	3
	OK	5		OK	3		OK	1		OK	1
	Pleased	3		Pleased	1		Pleased	2		Relieved	2
	Relieved	2		Very Happy	1		Feel results are accurate	2		Average	1
	Feel resutls are accurate	2		Obviously true	1		Glad it was done	2		Not worried	1
	Glad it was done	2		So far good	1		Confirmed	1		Peace of mind	1
	Very Happy	1					Relieved result was normal	1			
	Average	1									
	Obviously true	1									
	So far good	1									
	Confirmed	1									
	Relieved results were normal	1									
	Not worried	1									
	Peace of mind	1									
Neutral	No change	5	**Neutral**	No change	5	**Neutral**	No answer	1			
	None	2		None	2						
	No more thought	1		No more thought	1						
	No answer	1									

Figure 7.
NOTE: All emotions reported by parents of infants who referred on the screening when asked, "What emotions did you feel when you received the results of the hearing screening?"

	Combined Nurseries Response	N=		Well Baby Response	N=		Special Care Response	N=		NICU Response	N=
Positive	Fine	8	**Positive**	Fine	3	**Positive**	Fine	2	**Positive**	Fine	3
	Glad test was done	4		OK	1		Glad test was done	2		Glad for test	2
	Happy	3		Not scared	2		Happy	2		Happy	1
	OK	3		Not worried	1		OK	2		Not worried	1
	Not scared	2		Alright	1		Reassured	2			
	Not worried	2		Cool	1		Glad baby's not deaf (1 ear)	1			
	Reassured	2		No Alarm	1						
	Glad baby's not deaf (1 ear)	1		No concern	1						
	Alright	1		Normal	1						
	Cool	1		Regular for Babies	1						
	No Alarm	1									
	No concern	1									
	Normal	1									
	Regular for Babies	1									
Negative	Concerned	12	**Negative**	Concerned	4	**Negative**	Concerned	5	**Negative**	Concerned	3
	Worried	7		Worried	3		Worried	1		Worried	3
	Anxious	2		Crying needs re-done	2		Anxious	1		Anxiety	1
	Crying needs re-done	2		Don't know what it means	2		Did not understand	1		Didn't understand	1
	Did not understand	2		Sad	1		Disappointed	1		Disappointed	1
	Disappointed	2		Scared	1		Scared	1		Sad	1
	Don't know what it means	2		A lot of questions	1		Upset	1		Upset	1
	Sad	2		Couldn't catch my breath	1		Felt test wasn't accurate	1		Unsure	2
	Scared	2		Couldn't believe it	1		Nervous	1		Depression	1
	Upset	2		Hoped for a different result	1		Not clear what was going on	1		Thankful for life	1
	Unsure	2		Need to talk to my babies doctor	1						
	A lot of questions	1		Not too upset	1						
	Couldn't catch my breath	1		Uncertain	1						
	Couldn't believe it	1									
	Hoped for a different result	1									
	Need to talk to my babies doctor	1									
	Not too upset	1									
	Felt test wasn't accurate	1									
	Nervous	1									
	Not clear what was going on	1									
	Depression	1									
	Thankful for life	1									
Neutral	Nothing	3	**Neutral**	Don't know what it means	1	**Neutral**	Nothing	2	**Neutral**	Nothing	2
	Don't know what it means	1		None	1						2
	None	1		Not many	1						
	Not many	1		Not surprised	1						
Unclassifiable	Not surprised	1	**Unclassifiable**	Common result	1	**Unclassifiable**	Not too worried	1	**Unclassifiable**	Surprised	1
	Common result	1		Pediatrician said 9/10 times not accurate	1					Told nothing to worry about	1
	Not too worried	1									
	Pediatrician said 9/10 times not accurate	1									
	Surprised	1									
	Told nothing to worry about	1									

Figure 8.

NOTE: All emotions reported by parents of infants who referred on the screening when asked, "What emotions do you feel now (1-3 weeks following the screening) regarding the hearing screening results of your infant?"

	Combined Nurseries Response	N=		Well Baby Response	N=		Special Care Response	N=		NICU Response	N=
Positive	Hopeful	10	**Positive**	Hopeful	1	**Positive**	Hopeful	5	**Positive**	Hopeful	4
	Fine	8		Fine	5		Fine	2		Fine	1
	OK	5		Not worried	1		OK	4		OK	1
	Reassured	3		Ok once complete	2		Glad test was done	1		Reassured	3
	Glad test was done	2		Cool, fluid is normal	1		Good	2		Glad test was done	1
	Good	2		Don't think it'll be an issue	1		Feeling better	1		Not worried	1
	Not worried	2		Everything is OK	1		Feels good	1		Less anxious	1
	Ok once complete	2		More relieved	1		Figure it will be OK when done again	1		Less worried	1
	Cool, fluid is normal	1		Relieved	1		Satisfied	1		Pleased	1
	Don't think it'll be an issue	1									
	Everything is OK	1									
	Feeling better	1									
	Feels good	1									
	Figure it will be OK when done again	1									
	Less anxious	1									
	Less worried	1									
	Pleased	1									
	More relieved	1									
	Relieved	1									
	Satisfied	1									
Negative	Concerned	6	**Negative**	Still concerned	3	**Negative**	Concerned	3	**Negative**	Concerned	3
	Still concerned	3		Concerned more than at first	1		A little worried	1		Worried	1
	A little worried	1		Hoped result was different	1		Nervous	1			
	Concerned more than at first	1		Uncertain	1						
	Hoped result was different	1		Won't feel better until I know it's OK	1						
	Nervous	1									
	Uncertain	1									
	Won't feel better until I know it's OK	1									
	Worried	1									
Neutral	No concern	5	**Neutral**	No concern	5	**Neutral**	Nothing	3	**Neutral**	Don't know	1
	Nothing	4		Changed a little	1		Don't know	1		Nothing	1
	Don't know	2		Don't know what it means	1					Waiting for re-screen	1
	Changed a little	1		Needs repeated	1						
	Don't know what it means	1		Need to talk to baby's doctor	1						
	Needs repeated	1		Not surprised	1						
	Need to talk to baby's doctor	1		Unchanged	1						
	Waiting for re-screen	1									
	Not surprised	1									
	Unchanged	1									
Unclassifiable	Can't control it anyway	1	**Unclassifiable**	Can't control it anyway	1	**Unclassifiable**	Not too worried	1	**Unclassifiable**	Coping	1
	Coping	1									
	Not too worried	1									

Figure 9.

NOTE: Responses by parents when asked, "Did you received the results in writing or verbally?"

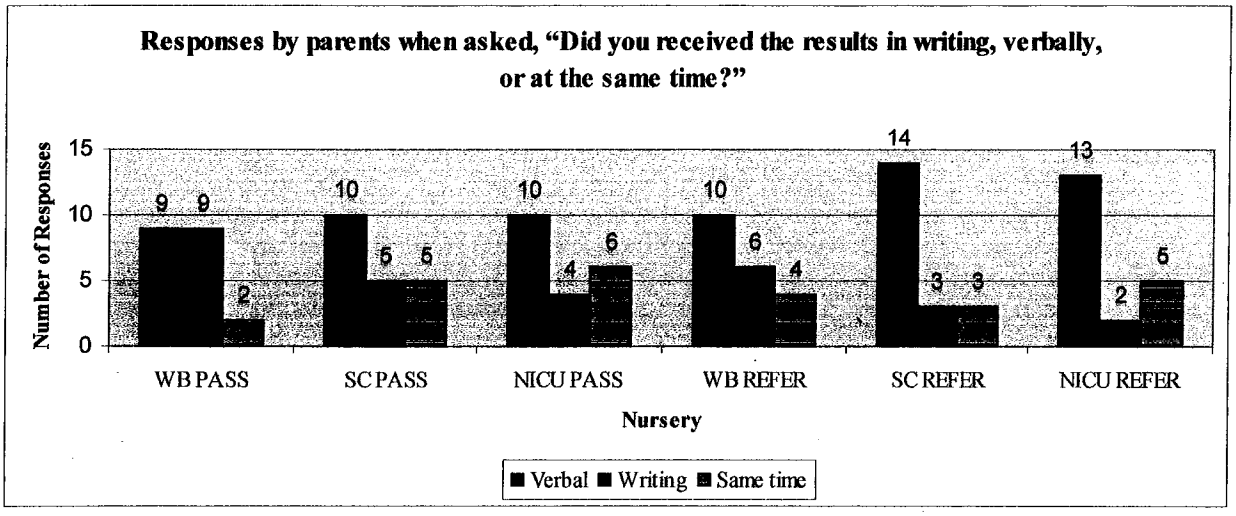


Figure 10.

NOTE: Responses reported by parents when asked, "If the explanation of the results was verbal, who explained the results to you?"

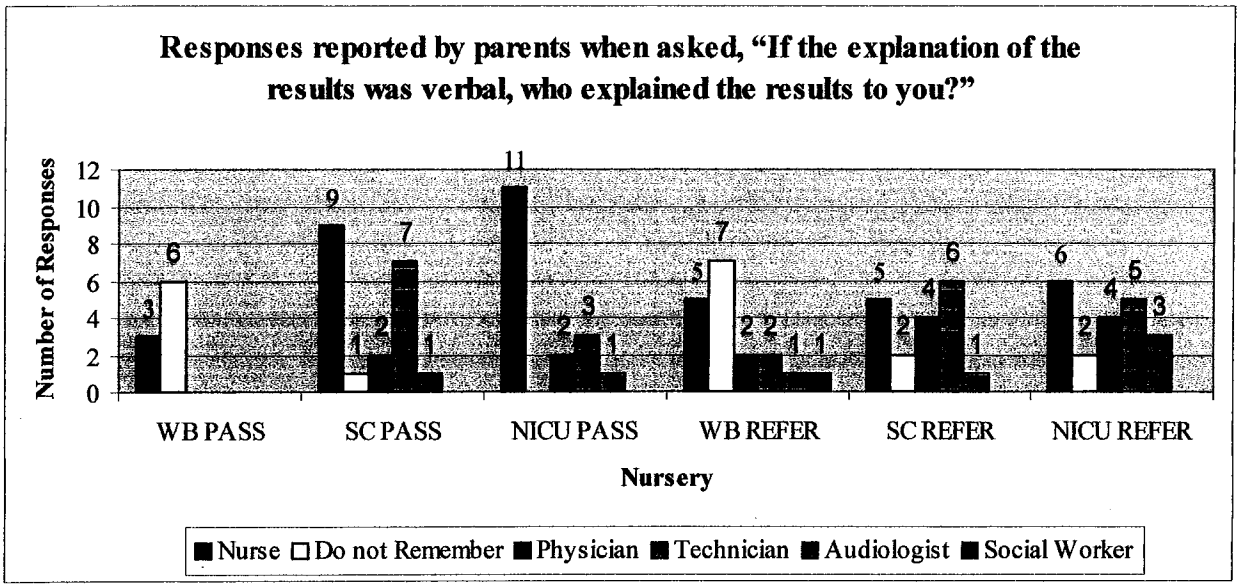


Figure 11.

NOTE: Responses reported by parents when asked, "Was the verbal/written explanation easy to understand?"

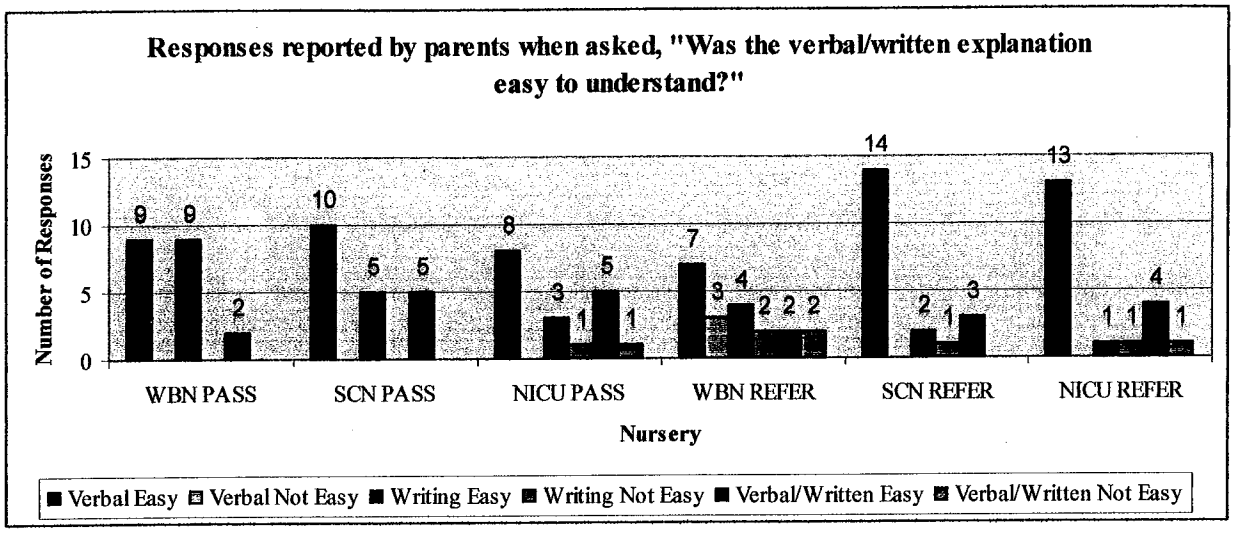


Figure 12.

NOTE: Responses reported by parents when asked, "Who do you think is the best professional to discuss hearing screening results with you?"

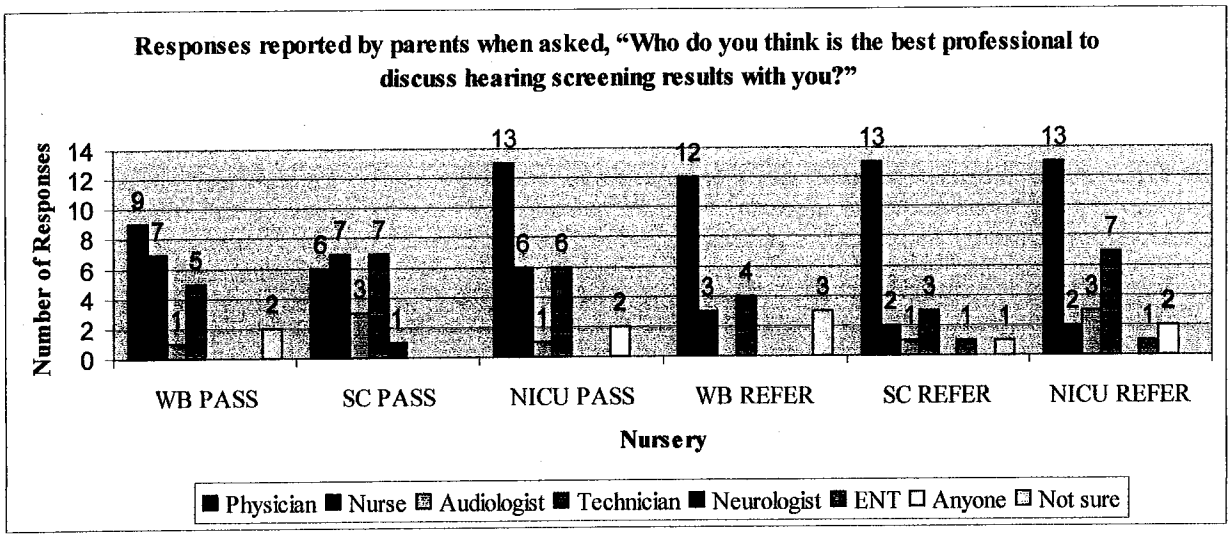
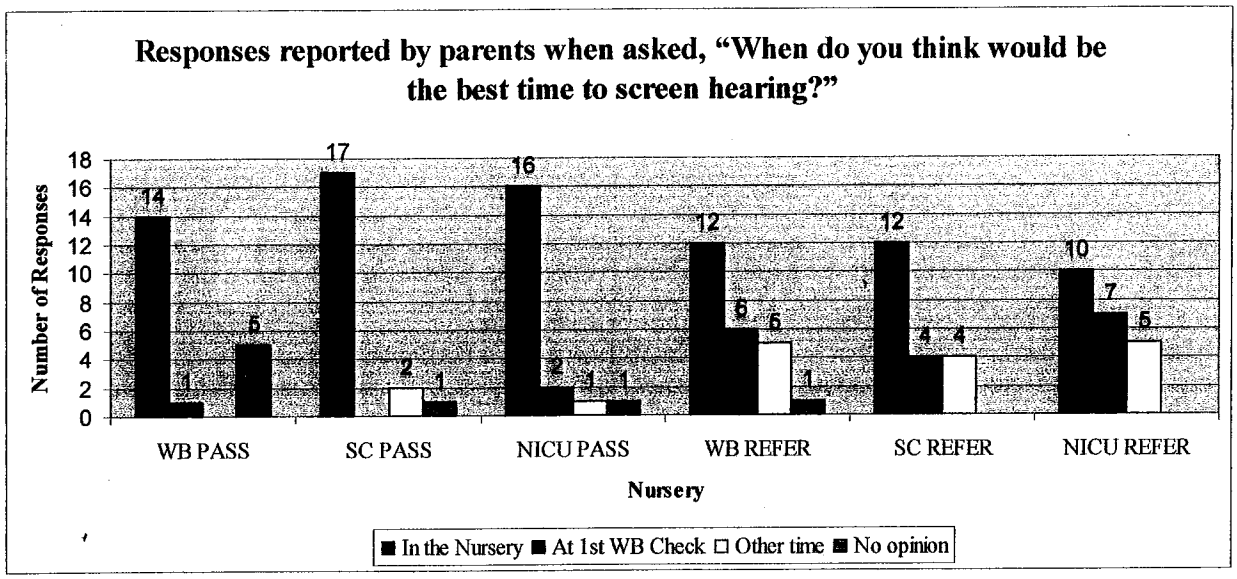


Figure 13.

NOTE: Responses reported by parents when asked, "When do you think would be the best time to screen hearing?"



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